The Experiences of African American Caregivers of People with ADRD in Rural South Carolina

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Study Background

ADRD in South Carolina

- ADRD 7th leading cause of death (U.S.); #1 for South Carolinians 65+
- Aging population intensifies impact
- 33% rural population, where ADRD prevalence is higher
- African Americans are 2x more likely to develop ADRD
    - less likely to receive diagnosis and treatment

Caregiving Burden & Structural Gaps

- Care relies on unpaid family caregivers
- ADRD caregiving is more burdensome
- 31.5% report worsened health due to caregiving
- Many experience unmet needs and limited provider guidance
    - 38.3% never asked about caregiving needs; only 22% about their own well-being
- ADRD cases increasing while caregiver pool shrinks

Aims and Questions

Specific Aims

- Document the personal narratives of African American ADRD caregivers related to their responsibilities, challenges, sources of support, and resilience.
- Identify unmet needs in caregiving, especially those overlooked by healthcare systems.
- Generate caregiver-centered insights to inform practitioners, community health workers, and fellow caregivers.

Research Questions

- **Scoping Review:** What is known about the experiences of rural Black caregivers of persons with ADRD?
- **Oral History:** What are the experiences of Black caregivers of persons with ADRD in rural South Carolina?

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Guiding Frameworks and Methods

Scoping Review (Arksey & O'Malley, 2005; Levac et al., 2010)

- On Black rural ADRD caregivers research to identify key themes and gaps in the literature.
- Conducted search in PubMed, Web of Science, PsycINFO, and Sociological Abstracts databases. Search yielded 669 studies to be screened, which resulted in 16 studies to be included.

Oral History

- Interviews to gather rich, qualitative data. Ideal for centering underrepresented voices, preserving community memory, and generating narrative-driven insights that can be used for education, advocacy, future research, and building stronger community ties.
- Are public and require direct engagement with communities.
- Conducted 15, in-person interviews. Recruited participants from three counties (Orangeburg, Sumter, and Fairfield) utilizing networks of community health workers, churches, and local health organizations. Conducting a thematic analysis on interview transcripts to identify salient themes.

Commitment to Community Engagement & Improvement

- This project is rooted in the understanding that NMDOH contribute to African Americans' higher rates of dementia and stress
  - Asks questions about environment that Black caregivers live in and how that shapes their experiences
- Oral history as a method requires direct community engagement
  - Outcomes to be shared with community partners
  - The interviews will be edited into a short recap video that will share findings with community partners and health organizations

Emerging Themes & Takeaways: Scoping Review

16 articles

- Only 3 articles focusing explicitly on rural Black caregivers
- May be reporting bias on level of mental health issues to avoid stigma
- Rural neighborhoods = stronger community ties
- African Americans have a greater level of burden and relief from interventions

Emerging Themes & Takeaways: Oral History

15 narrators

- Suffering in Silence
- Lack of access to resources, education, & help
- Patience as a lesson
- Difficulties taking care of self
- Unaware of Brain Health Network
- Driven to become advocates

CONCLUSION

Rural Black caregivers of persons with ADRD are **facing a major health crisis largely on their own**. They are both **severely understudied and underserved**. Facing **higher rates of ADRD with less access to resources** to assist in their caregiving process. In absence of institutional help, **they become advocates for their communities**, creating an opportunity to center them in implementing effective care interventions.

Implications & Future Research

The oral histories suggest that there are community members who are motivated to improve the caretaking experiences, and we should incorporate their voices more in communication about dementia and future community engagement efforts.